



RON CHAPMAN, MD, MPH
Director & State Health Officer

Vital Statistics Advisory Committee (VSAC)
Vital Records Protection Advisory Committee (VRPAC)
Joint Meeting
Meeting Minutes for Wednesday, January 9, 2013
9:00 AM



EDMUND G. BROWN JR.
Governor

ATTENDEES:

Convener: Krista Christian, MBA, Chief, Vital Statistics Unit

Committee Members:

Present: Jonathan Teague, MCRP, Malaika Singleton Duran, PhD, Emily Putnam-Hornstein, PhD, Veronica Wolgus (in place of Tony Agurto)

Phone: David Grant, PhD

California Department of Public Health (CDPH) Staff:

Present: Laura Lund, Science Advisor, Julie Turner, Cindy Tanaka-Fong, Emily Stotlar

CALL TO ORDER: The meeting was called to order at 9:05 AM

A/B. WELCOME/INTRODUCTIONS: Krista announced that this was a public meeting conforming to the Bagley-Keene open meeting act. Members of the public are allowed to attend and welcome to participate at the end of the meeting.

Krista informed everyone that the meeting was being recorded to assist with the minute taking. Krista introduced CDPH staff. Krista welcomed Emily Stotlar who previously worked in the Data Quality Management Unit on special projects but is transitioning into the Vital Statistics Unit.

No members of the public attended the meeting.

Research protocols are available for review on our Department's SharePoint site. Protocols are uploaded up to 3 weeks prior to the VSAC meeting and members were encouraged to download and review them early to avoid issues.

We received an announcement from Sue Holtby that she is withdrawing from the committee as she completed her 3 year term. We would like to thank her for her service. We currently have 7 members on the committee. We are still looking for new recruits. David Grant commented that he joined the committee the same time as Sue Holtby. He asked about the expected years of service. Krista responded it is 1-2 years for the VRPAC and 3 years for

VSAC. There is nothing in statute that says you cannot serve longer than the specified time.

C. APPROVAL OF MINUTES FROM THE PREVIOUS MEETING:

Jonathan Teague motioned to approve the November 14, 2012 meeting minutes. Emily Putnam-Hornstein seconded the motion. All Committee members voted to approve the minutes. There were no oppositions. There was one abstention.

D. VSAC RECOMMENDATIONS FROM THE PREVIOUS MEETING:

Attachment 1, the State Registrar's Response to VSAC Recommendations, is a recap of recommendations from the last meeting.

E. NEW BUSINESS:

Ten projects were reviewed.

The first project reviewed by the Committee was:

Project Title: "Maternal and Infant Health Assessment (MIHA)"

Principal Investigator(s): Paula Braveman, MD, MPH, Professor of Family and Community Medicine, University of California, San Francisco, School of Medicine

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-10-0819

Expiration: December 6, 2013

File(s) Requested: 2013 Custom birth dataset

Requested Identifiers: Select variables

Personal Contact: Yes

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: No discussion.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval. There were no oppositions. There was one abstention. Motion carried.

The second project reviewed by the Committee was:

Project Title: "Investigation of the Relation of Fine Particulate Air Pollution and Temperature to Mortality in California"

Principal Investigator(s): Rachel Broadwin, MPH, Research Scientist, Office of Environmental Health Hazard Assessment (OEHHA), California Environmental Protection Agency (CalEPA)

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-05-0246

Expiration August 2, 2013

File(s) Requested: 2008-2011 Death Statistical Master File (selected variables)

Requested Identifiers No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: No discussion.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend approval of the data request. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The third project reviewed by the Committee was:

Project Title: "The Program Monitoring and Evaluation of California's Family Planning Program: Family PACT"

Principal Investigator(s): Marina Chabot, Office of Family Planning, Development of Health Care Services

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-06-0310

Expiration: August 2, 2013

File(s) Requested: 2011 Birth Statistical Master File (entire file)

Requested Identifiers: Name, Certificate Number, Address

Personal Contact: No

Identifiers Released: No

History: New Research Project

VSAC Discussion: Concerns brought up by the committee included the release of marital status and SSN, the identity of the private investigator, and if a HIPPA waiver was needed. Clarification was made that the Private Investigator (PI) is aware we would not release marital status or SSN. The PI was identified as her signature was on the access agreement. Vital Statistics is exempt from a HIPPA waiver but they would need a HIPPA waiver as Medi-Cal is one of the providers. Julie confirmed that the project was approved by CPHS.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend the approval of the data. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: The Committee members all voted in favor of recommending the approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The fourth project reviewed by the Committee was:

Project Title: "National Children's Study"

Principal Investigator(s): Christina Chambers, PhD, MPH, Department of Pediatrics, Family and Preventive Medicine, and Skaggs School of Pharmacy and Pharmaceutical Sciences (SSPPS), University of California San Diego

Project Type: Continuing Project

CPHS Approval: Approved

Project No: 08-02-58

Expiration: February 1, 2013

File(s) Requested: 2011 Custom birth dataset (select variables with personal identifiers)

Requested Identifiers: No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request

VSAC Discussion: The committee wanted to know if the project had CPHS approval. Krista stated if it is pending, we would not release the data until we receive CPHS approval. Clarification was made that if the project was approved through February 1, we would let them know they can only use the data until February 1 unless there is a subsequent renewal.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

VSAC Vote: The Committee members voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The fifth project reviewed by the Committee was:

Project Title: "Out-of-Hospital Sudden Cardiac Death Records Review"

Principal Investigator(s): Benjamin Colburn, Electrophysiology Services, University of California San Francisco

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-06-0459

Expiration: October 4, 2013

File(s) Requested: Custom death dataset 2007-2013 (select variables)

Requested Identifiers: California identifiers

Personal Contact: Yes

Identifiers Released: No

History: New Research Project.

VSAC Discussion: David Grant commented that the proposal was brief and did not have much detail as it was not certain what they were proposing to do. It was his understanding they were asking to do 2 things:

- Obtain consent from us to contact the next of kin to obtain a tissue sample. This would involve the use of PID for contact information.
- Ensure the sampling of San Francisco is representative of deaths in SF by cardiac arrest

There is no information as how they would be contacting the next of kin.

Other committee members also expressed concern with the protocol.

VSAC Recommendation(s): Approve the data request. For clarification purposes, and since it involves human subjects, it was suggested we have the approval of CPHS in place first before we release the data.

VSAC Motions: Jonathan Teague motioned to review the protocol after we receive the approval from CPHS. The protocol would be brought back for committee's approval once we receive CPHS approval. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The sixth project reviewed by the Committee was:

Project Title: "Predictors of Long-term Outcomes in California Children with Central Nervous System (CNS) Tuberculosis (TB)"

Principal Investigator(s): Alexandra Duque-Silva, MD, California Department of Public Health, Tuberculosis Branch

Project Type: New Project

CPHS Approval: Requested

Project No.: Pending CPHS approval

Expiration: Pending CPHS approval

File(s) Requested: 2001-2011 Death Statistical Master File (select variables)

Requested Identifiers: Decedent's name

Personal Contact: No

Identifiers Released: No

History:. New Research Project.

VSAC Discussion: Comments included the small sample size. A suggestion was made that we could be flagged with the researcher's attention.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend the approval of the data request. David Grant seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The seventh project reviewed by the Committee was:

Project Title: "Mortality and Support on Online Social Media"

Principal Investigator(s): James H. Fowler, PhD, University of California, San Diego

Project Type: New Project

CPHS Approval: Requested

Project No.: Pending CPHS approval

Expiration: Pending CPHS approval

File(s) Requested: 2000-2010 Death Statistical Master File (select variables) Dr. Fowler will be using the same data set obtained for two of his projects.

Requested Identifiers: California identifiers only

Personal Contact: No

Identifiers Released: No

History: New Research Project.

VSAC Discussion: The Committee commented on how they would be linking the Facebook information based on the use of the name. A question was raised on what are the privacy agreements on Facebook accounts? They said they would not attach any data from the death file with Facebook, is there any way we can monitor this? As this is pending CPHS approval, the committee was curious as to what CPHS has to say. Another comment made was their response in stating they would not be using an outside contractor, but provided a description of the Facebook server. Jonathan made the suggestion that remain this until we get CPHS approval and we contact CPHS reviewer, asking them if they had any thoughts about this.

VSAC Recommendation(s): . After their discussion, it was decided CDPH staff will contact CPHS and discuss with appropriate staff who is responsible for this protocol.

VSAC Motions: Jonathan Teague motioned to review the protocol after we receive CPHS approval. Emily Putnam-Hornstein seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The eighth project reviewed by the Committee was:

Project Title: "A Binational Population-based Study of Birth Outcomes of Mexican-Origin Women Living in California and Mexico"

Principal Investigator(s): Sylvia Guendelman, PhD, University of Berkeley

Project Type: Continuing Project

CPHS Approval: Approved

Project No.: 12-08-0681

Expiration: October 4, 2013

File(s) Requested: 2008, 2009 Birth Statistical Master File (select variables)

Requested Identifiers: No Personal Identifiers

Personal Contact: No

Identifiers Released: No

History: Previous Data Request.

VSAC Discussion: No discussion

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Emily Putham-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. There was one abstention. Motion carried.

The ninth project reviewed by the Committee was:

Project Title: "Linkage of Medi-Cal Administrative Data with Data from the California Birth Statistical Master File"

Principal Investigator(s): Aldona Herrndorf, MPH, Department of Health Care Services

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-07-0571

Expiration: Determination of No Research

File(s) Requested: 2010 & 2011 Birth Statistical Master File (select variables)

Requested Identifiers: Name, Certificate Number, Address

Personal Contact: No

Identifiers Released: No

History: New Research Project.

VSAC Discussion: Committee expressed concern with data retention and wanted clarification on what they were going to do with the data once the project is completed.

VSAC Recommendation(s): Approve the data request with stipulation that the PI indicates how the data will be returned or

destroyed pending the project termination, pertaining to the data on the server.

VSAC Motions: Emily Putnam-Hornstein motioned to recommend approval of the data request. Jonathan Teague seconded the motion.

VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

The tenth project reviewed by the Committee was:

Project Title: "Environmental Health Tracking and Childhood Cancers in California"

Principal Investigator(s): Julia Heck, PhD, Researcher, University of California, Los Angeles

Project Type: New Project

CPHS Approval: Approved

Project No.: 12-05-0270

Expiration: August 2, 2013

File(s) Requested: 2010 and 2011 Birth Statistical Master File (select variables), 2010 and 2011 Death Statistical Master File (select variables)

Requested Identifiers: BSMF (Name, Certificate Number, Address), DSMF (Name, Certificate Number, Address)

Personal Contact: No

Identifiers Released: No

History: New Research Project.

VSAC Discussion: No discussion.

VSAC Recommendation(s): Approve the data request.

VSAC Motions: Jonathan Teague motioned to recommend approval of the data request. Emily Putham-Hornstein seconded the motion.

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VSAC Vote: Committee members all voted in favor of recommending approval of the data request. There were no oppositions. Motion carried.

F. ITEMS FOR DISCUSSION: Krista asked the Committee to refer to Item F, Recap of Data Requests Approved in the Vital Statistics Unit, Attachment 3. Twenty-five data requests that did not require VSAC/VRPAC review were reviewed and approved by the Health Information and Research Section.

G. PUBLIC COMMENT: There were no members of the public attending the meeting.

H. AGENDA ITEMS: Krista asked the Committee if there were any agenda items for the next meeting. There were no agenda items.

I. ADDITIONAL DISCUSSION: Malaika Singleton Duran told the Committee she is representing the Legislature, that she would not be voting or making any motions.

J. MEETING ADJOURNMENT: Emily Putham-Hornstein motioned to adjourn the meeting. Jonathan Teague seconded the motion. Committee members all voted in favor of adjourning the meeting at 10:05 A.M.